

The Lived Experiences of a Female with Disability in Jhamak Ghimire's *Jeevan Kada ki Phool* (*A Flower in the Midst of Thorns*)

Mahendra Kumar Budhathoki, Ph.D.*

Abstract

Some children get births with impaired, and some may lose their physical organs due to diseases or accidents. Such persons are described as persons with disability or differently able persons. The society limits them in narrow places, discriminates them from the so-called able persons and abuses them more than the animals. This paper discusses the lived experiences of a rural female with disability in Jhamak Ghimire's Jeevan Kada ki Phool (A Flower in the Midst of Thorns). This article attempts to answer how a rural society treats to a girl with disability. This paper has used disability studies as the research approach; it is a qualitative textual analysis. The major finding is that a girl with disability has suffered so much pains and tensions due to social, cultural and religious traditional assumptions. She has been discriminated as a double subaltern: one as disabled and next as a female. Since her babyhood, she has been discriminated from her family members and other people of the society. Persons with impaired are also humans but the society's eyesight is disability to see at them. The society creates more problems to persons with impaired rather than their physical conditions. Even if persons with impaired perform remarkable works, the so-called able persons describe them as unusual and inspirational, and all their works and achievements are connected with their impaired. This paper has used the social model of disability studies. It may be useful to the academic readers and other public persons. Jhamak's lived experiences may transform the traditionally mind-set assumptions of people to persons with disability, and person with disability can live as humans in the society.

Key-words:

lived experience, disability, impaired, discrimination, social injustice

Introduction

This study aims to explore the lived experience of a rural female with disability in Jhamak Ghimire's *Jeevan Kada ki Phool (A Flower in the Midst of Thorns)* from a disability studies perspective. This paper discusses how a rural female with disability experiences, feels, perceives, understands and makes sense of the experience in the society. The lived experience refers to the personal knowledge about the society and/or community gained from face to face interaction being directly involved in everyday activities. It is a firsthand experience involved in the society. A person lives and encounters everyday events in the environment of a society; she experiences and makes sense of her experience gained in the society. It provides an understanding of the experience of a female with disability lived in a society; the feminist disability perspective is used to analyze the socio-cultural production of gender and disability in Ghimire's autobiographical work *Jeevan Kada ki Phool (A Flower in the Midst of Thorns)*.

Disability studies has been an important area of intellectual enquiry in literature. The concept of disability is social construction. Society abuses, discriminates and exploits the people with impaired by calling them disable. The studies of disability has not been only limited within health sciences and sociology, but also extended to literature having experiences of people with disability. Derek Attridge says, "[Literary works] are capable of taking us through an intense experience of these other-directed impulses and acts", and Synder and Mitchell argue that literature by *definition* 'makes disability a social rather than a medical phenomenon' (Cited in Alice Hall 'Disability and Modern Fiction' 5). The speaker and/or a character speaks about disability through first person narrative perspective and the society or other characters' behaviours toward the character with

disability also indicate the treatment to disability in literary works. This paper explores the voices of a female suffered from cerebral palsy relating with social understanding of disability and rurality in Jhamak Ghimire's autobiographical text *A Flower in the Midst of Thorns*. Ghimire having the problem of cerebral palsy expresses her own experience based on the phenomenology of disability. Phenomenology is a powerful means to transfer the experience of people with disability. How does Nepali society really describe disability and treat people with impaired? What does rurality mean in the lives of people with disabilities? How does society treat people with impaired and female as the 'other' (very unusual, different in character or quality from the normal or expected)? Ghimire's work presents public debate about the representation of physical disability and gender in literature. There is a double discrimination of a female with disability; one is the female body and next is the disabled physical body. There is the representation of the social marginalization of a female with disability in literature. This paper aims to explore an intellectual debate about the amalgamation of gender and disability theory in literature.

Reviews of the Related Literature

This literature review incorporates issues of disability and lived experience. Although the literature covers diversity of disability, this research mentioned incorporates the general concept of disability studies and the viewpoint of the social model. Disability studies talks about "the social marginalization of people with disability" (Hall 4). A disability study discusses the issues of disability as the marginalized and disadvantaged constituency, a minority group and a social problem (Watson et al. 3). Disability studies theorizes the experiences of persons with disability. Disability studies does not treat disease or disability, hoping to cure or avoid them; it studies the social meanings, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and expression, attacking the widespread belief that having an able

body and mind determines whether one is a quality human being. More specifically, disability studies names the states of social oppression unique to people with disabilities. (Siebers 3-4)

Disability studies raises questions of social discrimination to persons with impaired. Disability and impairment are two words that are used to people who have lost by birth or accident and/or weak parts of the body. Medical personnel also use the ‘disability’ to the impaired ones. Impairment means having defective mechanism of the body, and disability means the social behavior for restriction to the impaired people who are excluded from social activity. Hall mentions, “Disability is created through a social process: through the relationship between an individual with impairment and the society in which they live. [...] They are disabled by the lack of provision of ramps and appropriate access facilities” (21). The concept of disability is socially constructed. People with impairment are excluded by society from different activities. Siebers says, “Disability is not a physical and mental defect but a cultural and minority identity” (4). No one can do all things, and people with disabilities can do at least a work in life. “The [disability] field emerged in the 1980s, part of a cluster of politicized identity-based interdisciplinary fields of study that arose from rights-based, social-justice-influenced knowledge building and disseminating initiatives. Such fields theorized as well as actualized greater inclusion and equality in the academy” (Garland-Thomson 916). Social attitudes, behaviours, policy and structures exclude people with disability from mainstream activities. The disability is not nowadays personal misfortune and medical problem but has been a rights-based issue and inclusion in public places. People with disability are the minority groups in Nepal and they are not addressed appropriately in societies and country.

People with disability are described from mainly three models, namely, charity and welfare, medical, and social. In charity and welfare model, people with disability are considered as “a symbol of pity, handicapped and unable to function fully, [and] ... need assistance from other people and society” (Ojha 13). “The medical models defines disability as a property of the individual body that requires medical intervention” (Siebers 25). It indicates something lacking in bodies because of accidents, diseases and other impaired health conditions. The social model defines disability as a social attitude and treatment of concerning inclusion and exclusion in social activities. “The social model emphasi[zes] on the material and structural causes of disabled people’s disadvantages. This has led to the introduction of numerous legislative measures and policy initiatives to address the various economic and social deprivations encountered by disabled people across the world” (Barnes 23). It discusses on “everyday experience of disablement” (24) in public places and at homes. Here is the discussion of the social model, but not other two models. The people with disability do not have access in public places’ (like schools) infrastructure such as buildings, schools, learning materials in majority of educational institutions (CBS 2010/11). People with disability experience discriminatory behaviours everyday. Oliver and Barnes analyzed disability studies and the meaningful inclusion for people with disability in works (547). The exclusion and inclusion debate is in public places like schools, hospital.

There is a lack of desire for change and avoidance of even unintentional discrimination to persons with disabilities. From the viewpoint of social model, society, specially non-disabled people, restrict social and material participation in public places, and fix them in private places. Oakley discusses the discursive psychology and loneliness of persons with disabilities; “the loneliness constitutes a person’s *perception* of social isolation” (3). Wood mentions, “Loneliness is both individual and social. It is individual because it refers to the person as separated; it is social because what the person is separated from is

other people” (cited in Oakley 4). Non-disabled and disabled individuals should collaborate with each other to make sense of their experiences in real lives.

People with disabilities are from urban and rural areas; their problems and challenges somehow different as per their geographical spaces as well as socio-cultural structures. People with disabilities see differently their own lives in the rural areas in comparison with urban. Soldatic and Johnson discusses about disability in the context of identity, gender, belonging and rurality. They attempt to focus on “knowledge and understanding of rural living for people with disabilities” (1). This idea helps to explore the lived experiences of persons with disabilities of rural areas. Ghai talks about disability from different perspectives in the context of India; “DS [Disability studies] perspectives enlighten how individual designated ‘disabled’ are treated in a manner that diminishes their economic, interpersonal, psychological, cultural, political and physical well-being, relegating them to membership to minority group” (2). She incorporates the issues raised from real people as well as literature within Indian contexts. “Feminist disability studies [...] adds disabled women’s experiences [...] in disability studies” (Hall, “Feminist Disability Studies” 1). Disability studies discusses the issues of gender in disability. “women and the disabled are portrayed as helpless, dependent, weak, vulnerable, and incapable bodies” (20). Dhungana presents the experiences of women with disability in Nepal; she used qualitative interviews with 30 women with physical disability in Kathmandu Valley connecting different aspects of their lives. She concludes, “[...] disabled women are positioned at the lowest social level. They are cast down, stigmatized, rejected, excluded from family, community and from the government authority” (144). She chose this method to explore their real experiences, and she purposively select Kathmandu Valley for the study area but there would be the vast gap in experiences of disabled women comparing with disabled women from outside the Kathmandu Valley.

The above-mentioned reviews discuss about disability studies especially from the social model perspective. Soldatic and Johnson connect the issue of disability with rurality. Disability in education concerns more with students with disability. After reviewing the research, the research questions arise what the condition of rural persons with disabilities is and what they experience in the rural society. Although the literature review presents disability in different contexts, this paper focuses on the experiences of a rural female with disabilities in the community she lived. The research gap is to explore the lived experiences of a rural female with disabilities and the conflation of the female body, femininity and disability in Ghimire's *A Flower in the Midst of Thorns*. This research indirectly forces people to change their interests and interventions in building concepts, thoughts, infrastructure and policy to facilitate and support persons with disabilities.

Research Methodology

This is a qualitative narrative study. Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks that informs the study of the research problems addressing the meaning individuals or groups ascribe to a social or human problem” (Creswell 35). Narrative research “as a method begins with the experiences as expressed in lived and told stories of individuals” (Creswell and Poth 110). Narrative approach has been the method for the study, and is used for the procedure of analyzing the experiences expressed by a person with disabled. “ The focus of narrative inquiry is not only valorizing individuals’ experience but is an exploration of the social, cultural, familial and linguistic narratives within which individuals experiences were, and are, constituted, shaped, expressed and enacted” (Clandinin 18). It makes the sense of expressing ‘what happened’ to a person. It examines the experience of a person with disabled focusing her struggles for rights and identity. A narrative study tells of individual experiences in a particular social cultural situation, and analyzes the sense of those experiences. Disability

interpretive framework is used in this research paper, and it is a textual analysis. There has been a use of inductive method developing ideas related with disability through analyzing the text. The researcher read the text thoroughly, coded and organized themes and interpreted the collected data. The sorted out data were reduced them to few categories, made sense of data through textual analysis. This paper did not discuss much the disability theory, but it has used disability theory as the interpretive framework in the discussion of Ghimire's *A Flower in the Midst of Thorns*. The social model differentiates disability from impairment. This paper has discussed disability through the social model in the contexts of rurality in her text.

The Exposition of Lived Experiences of a Female with Disability

Jhamak Ghimire is a female having cerebral palsy, and lives in rural community of Nepal. It means she is a rural female with physical disability. Ghimire has written her lived experiences of being a female and disability in traditional patriarchal rural community of Nepal. The environment where she got birth is not favourable for persons like Jamak. She has openly expressed her experiences encountered in everyday events in her life. She is double defect: one she is a female and next she is disabled. Traditional patriarchal rural community treat her as animals: "I couldn't tell whether it was an animal's life or a human being's that I was pursuing. [...] I lived a life devoid of sensitivity; a life that feels no pain, no colour and there is no love for the world ..." (2). She suffered too much in the society, and "it was almost beyond tolerance". This expression shows how a rural female with disability lives her life. People thought she suffers in this life due to her sinful acts in her previous life and God punished her. This society treat her ("a tender, delicate and innocent little girl") badly. She "had no alternative except to suffer without a murmur of protest". She could not speak and write to communicate to others. "My fingers were seemingly devoid of a capacity to stir even a

little. My lips were eager to speak, but not a word or sentence came out of them. My legs did not have the capacity to support my body-weight either. [...] As I saw cows and goats bleating or grunting there, I had a feeling that my life was not much different from theirs” (16-17). Her life was difficult because of disability discrimination. Her father and mother did not allow going outside and playing with other children because they thought she was a disabled girl: “I realize that the pleasures of infancy that all the other children enjoyed in life were denied to me forever”, and “they wanted me not to cross the limits of behavior drawn by them” (26). Her family members discriminate her from their other children. She “could at least crawl [herself] forcibly and move up to a few hands (cubits) distance away, but even that was not liked or appreciated by any of parents or elders” (27). She was mockingly called “a *saapey*- a slithering snake”. The villagers who were superstitious, uneducated and poor also called her *saapey*. Her parents were also rural people who never learnt how to behave a girl child with disability. Her father shouted, “What’s the use of your learning and reading?” (28). She used to write on the open space with her feeble toes, and she became so happy when she wrote a Nepali letter ‘ka’ that she silently and inwardly learnt from her younger sister. Her father taught her younger sister writing letters but not her. She used pebbles, charcoal and sticks to write letters with the foot on the open field as the copy. The superstitious people believed that drawing lines with charcoal at home leads to bad fortunes. Therefore, her parents scolded her many times. She used to go near her younger sister to learn something but her parents kept her distance from younger saying not to disturb. It means how rural people treat their crippled children. They always named her as a “fallen girl, a *saapey*”.

The rural people including her parents wished her early death rather than the miserable crippled body. They never supported her for living as a human being. “Whoever came to our house those days would wish I were dead rather than living such an extremely horrible life. [...] The only solution to everything was my death” (32-33). The rural

villagers were inhuman and cruel to the person with disability like her. She felt a traumatic shock and experience in her childhood life. It is still thought that persons (like Jhamak) with disability have no uses of going to schools. However, Jhamak had a keen interest to recognize letters and go schools. Her parents used to discourage her to learn letters, and they never gave her a pen and a copy for writing. She learnt to write the letter of Nepali consonant 'ka' on dust with her toes- "I had broken innumerable twigs time again in order to learn writing this letter and I bruised the tender skin rubbing against the soil. However, my toes bled when I practised writing by dipping them on the dew drops collected on the bowl" (42). The persons with disability have been being 'insult and injury' for ages. This is unbearable to her; this is a lived experience of a person with disability.

Non-disabled people usually abuse, scornfully remark and insult persons with disability. "People want to insult, dominate and hate the physically weak and disabled persons" (57). They mock females with disability more than males. People think persons with disability cannot do anything and they are burden for the earth. People consider that persons with disability are punished because of their sinful acts in their previous births- "those who have committed sins in their previous births are born either dumb or half-wit, or with a physical infirmity or as a woman in their present lives. Likewise, everyone held the belief that I had been a great sinner in my past life, and as a result, was reborn in this life not only with my physical deformities and non-functional limbs, but also a woman" (57). Such religious beliefs give pain in the lives of persons with disability. Even people did not like to see her because believed she brings misfortunes in their lives. "Superstitious pregnant women in our village filled with the apprehension that they might give a birth to a physically disabled child like me if they cast their eyes on me, would either avoid looking at me altogether or walk at a safe distance away from me." Villagers did not allow her mother to touch their babies. Such behaviours trouble her.

Poverty makes disabled people's lives more miserable. There is a significant difference in the lives of rich and poor people. Jhamak used to wear dirty worn jute pyjama; it indicates a sign of poverty in the society. Jhamak is a girl with cerebral palsy; people including her family members discriminate her from other so-called abled-persons. She thinks, "Am I not a human being? If all of us are humans, why is a distinction made between me and the others? [...] I had been disregarded and discarded by the society as a worthless being' (76). She was discriminated because she is a poor female with disability. She has worn a torn and tattered jute pyjama that could not cover her private sexual organs. Men would make that fun and tease her by throwing pebbles or mud-balls at her sexual organs. They have abused her frequently because she is from a poor family, she is a female and she is physically disabled. Those abusing discriminating behaviours to her "made a more painful impact on her mentally than physically" (82). This shows how a female with disability experiences in a rural area of Nepal. Her father like others used to think a disabled person has no work of going to schools. When Jhamak asked a pen and a copy for learning to read and write letters, "he bet [her] with a stick" (83). He had given her younger sister reading materials but not to her. This happened because of her physical disability. She accepts, "When everything about me had started being observed from the viewpoint of infirmity and disability, I had imperceptibly begun to experience a kind of pain in life" (93). She cannot speak but grin to express her emotions to them. She was placed as "the most neglected, most marginalized even amongst those marginalized ones" (94). The physically non-disabled people dominate persons with disability- "Aren't the dumb and deaf human beings? Then why such a discrimination? [...] Are the dumb and mute people not humans? If they are humans, why were they discriminated against like that? Yes, I had to face similar discriminations." Such behaviours to persons with disability show the nature of a backward society. The society where Jhamak raised is a rural undeveloped and disadvantaged area of Nepal. She was a double subaltern person because she is a disabled person and a female- "Even as it is I

was dumb and mute; and, on the top of it I was woman, a female. I would be identified as a dumb and mute woman” (95). People used the word *laatee* (dumb) to call her. They scold “this type of women”, and “worthless caste”. She has been oppressed “by the so-called civilized and clever people”. They took her an living object and toy of entertainment and ridicule for them. She had to face much discriminatory behaviour of the so-called abled people- “I had to fight battles against all barriers-religious, cultural and social”. A person with disability is not treated as a human “although born in an upper starta of the caste-hierarchy”. Even educated, civilized and cultured people show their behaviour “under the influence of untouchability as a custom” (99). Their lived behaviours discriminate between the differently able persons and the so-called non-disabled ones.

When Jhamak became a young female, she suffered much from sexual abuse. Men used to tease her because she could not strongly protest against them; “people would target at [her] and talk much nonsense. Some would be quite naughty and poke [her]. [She] would be the object of ridicule or talk” (106). She was so much suffered from sexual abuse, and she “still feels pained to remember those moments, [she] even feel tickling”. She was doubly sexually harassed because she was a female and a disabled in patriarchal rural area.

When she has struggled so much to be able to write letters with her toes, people think her as “an unusual girl who wrote with her toes”. She is unusual for the so-called able people who think it is not possible to write with toes of persons with cerebral palsy. When she became as newsworthy, people take her as an inspirational source to others. Now Jhamak is a great literary and creative writer and people change their behaviours to her; they respect her. She has raised from various pains and tensions caused by people’s discriminatory behaviours to her (rural disabled female). People still show pity even to the eminent intellectual persons with physical disability; people link ‘the emotion of pity

with the able person with impaired and his/her work. “The society still look[s] at [her] as a pitiable disabled girl. Every deed [she] performed is linked with her disability. No matter how educated and cultured people might have been, their mentality is still savage” (168). People think that persons with disability cannot do any things and are burden of their own lives. If some persons with disability perform some remarkable deeds, the so-called able persons link their deed with infirmity and disability, and describe as unusual and inspirational source for others. The persons with physical disability can perform many things with their mind and intellect but not with physical body. Have the so-called able persons performed well in all areas? Certainly, they are not able to perform all things. People look at her with pity, and her all performance and achievement are connected with disability; it is unfair. Even educated and cultured people look at persons with disability with their hateful and pitiful eyes, even if they cannot express it publicly. They do not take persons with disability as complete humans. Jhamak finds the society’s eyesight is disabled to identify the humanness and ability of persons with disability as the non-disabled ones. People with disability are tortured much more because of social attitudes rather than their physical problems. The society isolate, discriminate and abuse persons with disability. The society makes their lives more complex by discriminating in different social functions.

Conclusion

This paper discusses the lived experiences of a rural female with disability in Jhamak Ghimire’s autobiographical text *A Flower in the Midst of Thorns*. Jhamak herself is a rural female with cerebral palsy. This autobiographical work is just like an in-depth interview with a person with disability. She has expressed her lived experiences from the childhood. She suffered so much pains and tensions in her life. She is a double subaltern human; she is first a female and a disabled one. She was badly treated from her parents

and villagers. If the family and the society behave her as other humans, she would not suffer much like animals. She was maltreated although she had not her fault. They suffer much socially, culturally and religiously in the lived contexts. Therefore, the problem of persons with disability is more in the society's disabled eyesight rather than the physical weaknesses. This article talks about the lived experiences of a rural female with disability in Nepal from the viewpoint of disability studies, but not other viewpoints. It discusses only the issue of disability, but not other issue in this autobiographical work.

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

Works-cited

- 1] Barnes, Colin. "Understanding the Social Model of Disability: Past, Present and Future." Eds.
- 2] Nick Watson, Alan Roulstone and Carol Thomas. *Routledge Handbook of Disability Studies*. London and New York: Routledge, 2012. Pp. 12-29.
- 3] CBS. *Nepal Living Standard Survey*. Kathmandu: Central Bureau of Statistics, National Planning Commission Secretariat, Government of Nepal, 2010/11.
- 4] Clandinin, D. J. *Engaging in Narrative Inquiry*. Walnut Creek CA: Left Coast Press, 2013.
- 5] Creswell, John W. *Qualitative Inquiry and Research Design: Choosing Among the Five Approaches*. 3rd ed. Thousand Oaks CA: Sage, 2013.
- 6] Creswell, John W. and Cheryl N Poth. *Qualitative Inquiry and Research Design*, 4th edit. London: Sage Publication, 2018.
- 7] Dhungana, Bishnu Maya. "The Lives of Disabled Women in Nepal: Vulnerability without

- 8] Support". *Disability and Society*. 21.2. Routledge, January, 2006. Pp. 133-146. DOI: 10.1080/09687590500498051
- 9] Garland-Thomson, Rosemarie. "Disabilities Studies: A Field Emerged". *American Quarterly*, Vol. 65.4. The John Hopkins University Press, December, 2013. Pp. 915-926.
- 10] Ghai, Anita, Ed. *Disability in South Asia: Knowledge and Experience*. India: Sage publications, 2018.
- 11] Ghimire, Jhamak. *Jeevan Kada Ki Phool (A Flower in the Midst of Thorns)*. Translators Nagendra Sharma and Safal Sharma. Kathmandu: Oriental Publication, 2012.
- 12] Hall, Alice. *Literature and Disability*. London and New York: Routledge, 2016.
- 13] *Disability and Modern Fiction: Faulkner, Morrison, Coetzee and the Nobel Prize for Literature*. U K: Palgrave Macmillan, 2012.
- 14] Hall, Kim Q. *Feminist Disability Studies*. Editor. Bloomington and Indianapolis: Indiana University Press, 2011.
- 15] Oakley, Lee. *Exploring Student Loneliness in Higher Education: A Discursive Psychology Approach*. UK: Palgrave Macmillan, 2020.
- 16] Ojha, Gaurav. Ed. *Disability in Nepal: Taking Stock and Forging a Way Forward*. Kathmandu: Disability Research Centre Kathmandu University. 2018. www.unicef.org/nepal/reports/disabiliti-nepal
- 17] Oliver, Mike and Colin Barnes. "Disability Studies, Disabled People and the Struggle for Inclusion". *British Journal of Sociology of Education*, 31.5. Routledge, 2010. Pp. 547-560. DOI: 10.1080/01425692.2010.500088.
- 18] Siebers, Tobin. *Disability Theory*. The United States of America: The University of Michigan Press, 2011.
- 19] Soldatic, Karen and Kelley Johnson, Eds. *Disability and Rurality: Identity, Gender and Belonging*. London and New York: Routledge, 2017.
- 19] Watson, Nick, Alan Roulstone and Carol Thomas, Eds. *Routledge Handbook of Disability Studies*. London and New York: Routledge, 2012.

Author

*Mahendra Kumar Budhathoki, Ph.D. is an Assistant Professor at the Campus of International Languages, Tribhuvan University, Kathmandu, Nepal.